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Published in:
Journal of Rehabilitation Medicine

DOI:
10.2340/16501977-0182

J Rehabil Med 2008; 40: 347–354

ORIGINAL REPORT

NEEDS, PROBLEMS AND REHABILITATION GOALS OF YOUNG CHILDREN WITH CEREBRAL PALSY AS FORMULATED IN THE REHABILITATION ACTIVITIES PROFILE FOR CHILDREN

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Objective: **To describe the content of needs, problems and goals of 41 Dutch children with cerebral palsy using the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) as a classification system. To evaluate the adherence of formulations of needs, problems and goals to specifications of the Rehabilitation Activities Profile for Children.**

Methods: **Raw text data were extracted and organized. Two raters independently weighed the entries' quality against the specifications and linked the extracted content to ICF-CY categories.**

Results: **In 12% of the reports no needs, and in 24% no principal goals, were formulated. Needs mostly pertained to the activities-and-participation domain (65%), whereas problems and goals covered all 3 ICF-CY domains. None of the needs were prioritized and 79% met the quality criterion of description of a problem/desire. Twenty-four percent of the problems were described in the activity-and-participation domain and 83% referred to a treatable problem. Fifty-six percent of the goals were formulated in terms of intended result/effect and 63% as child/parent actions.**

Conclusion: **Insight is provided into the content of rehabilitation programmes for children with cerebral palsy. To optimize the quality of the reports, research on reasons for non-adherence to specifications of the Rehabilitation Activities Profile is needed.**

Key words: goal setting, rehabilitation report, cerebral palsy, collaboration, paediatric rehabilitation, ICF-CY, integrated treatment plan, communication.

J Rehabil Med 2008; 40: 347–354

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Submitted April 18, 2007; accepted January 9, 2008

INTRODUCTION

In paediatric rehabilitation, professionals from diverse organizations, such as medical and rehabilitation centres, special schools and allied healthcare facilities, work closely together to meet the often-changing complex needs of children with cerebral palsy, as well as those of their parents. Close collaboration between the members of the specialized teams (1–7) and coherent care co-ordination (8) are considered crucial to the quality of children's healthcare. Nowadays, several countries espouse these collaboration practices (9–13), resulting in various models of (mandatory) collaboration. These various models of collaboration have since been implemented and evaluated nationally (7, 8, 14–17).

Communication is fundamental in the collaboration process: in a review of the literature we found that poor interactive procedures impedes, and good practice facilitates, collaboration among professionals and the exchanges with the child's proxies (18). Poor reporting and poorly prepared team meetings tend to hamper communication and hence interfere with collaborative efforts (1, 5). Conversely, the following factors are mentioned as facilitating the communication in multidisciplinary teams: optimal information sharing, appropriate communication skills, explicitly formulated goals, the categorization of information, a transparent delineation of the roles of the various people involved, the use of a common language and a common frame of reference (18).

In most paediatric settings individualized, integrated treatment plans are used to optimize team communication and thus the care for children with multiple disabilities. Both the international literature (1, 19, 20) and Dutch reports (21, 22) acknowledge the need for such tailored, joint plans as the basis for sound care planning and delivery.

To help standardize interdisciplinary paediatric treatment plans in the Netherlands, in 2001 the Rehabilitation Activities Profile for children (Children's RAP) was developed and implemented (20). This provides professionals and parent(s) with a common language describing the child's and parental abilities and a common frame of reference for discussing their respective needs. In this way it helps all parties better to verbalize actual problems during the (annual or semi-annual) team conferences. The instrument further serves as a checklist and intends to prevent team members from forgetting to report relevant infor-

 doi: 10.2340/16501977-0182
 ISSN 1650-1977

mation or adding irrelevant information (23). Lastly, it guides the team towards the formulation and subsequent evaluation of tailored interdisciplinary rehabilitation goals.

The Children's RAP is divided into 3 sections:

(i) *general information*, comprising the particulars of the child and his or her proxies[1];

(ii) *current situation* delineating recent needs, impairments and abilities of the child and his or her proxies; and

(iii) *team-conference conclusions* describing the principal problem and the shared principal goal.

In this way the perspectives of all involved parties are incorporated in the child's rehabilitation plan. A need has been defined in the Children's RAP manual as a concept describing a problem that hinders the child or parents in daily life or describing the wishes or expectations the child, parents or environment have regarding treatment or education. The perspective of the professional team members, i.e. the rehabilitation and educational professionals, is represented in the definition of the principal problem. A principal problem has been defined in the Children's RAP manual as a concept that describes the currently most important problem that hinders the child or parents in daily life or describes the aspect that hinders or stagnates the child's development at present or in the future. After the needs and problems have been established, the profile recommends that the parents and professionals should jointly discuss and formulate the principal goal. The principal goal is defined as the effect, or result, that the team and the parents together aim for. The principal goal is directional for the discipline-specific treatment and education goals and is phrased in terms of children's and parental activities.

At present, all Dutch paediatric rehabilitation settings use the Children's RAP to structure the treatment plans and team conferences of the children treated. This instrument supports an interdisciplinary team approach, which is regarded as the optimal model of team activity (1, 6, 9, 23). However, for the Children's RAP to be effective, the basic requisites and specifications described in the manual need to be followed (Table I). Despite the adopted use of the Children's RAP in Dutch paediatric rehabilitation, there is currently no information about how well the Children's RAP is being used in clinical practice. Information on how the children's RAP is currently being used might provide useful insights into improvements needed to achieve optimal adherence to the specifications of the instrument. Furthermore, we need to know how the Children's RAP is actually used in practice before the information captured in the Children's RAP can be used in future research to evaluate treatment planning, service use, and paediatric rehabilitation outcomes. With the current study we sought to assess the quality of the Children's RAP reports of young (4–8 years) children with cerebral palsy as completed by teams in 5 multidisciplinary paediatric rehabilitation settings in the Netherlands. In addition, this study aimed to describe the content of the reports of these children to provide information on what paediatric rehabilitation is like for young children with cerebral palsy in the Netherlands. We explicitly evaluated how well the formulations of the children's and parental (proxy) needs, the principal problems and the (shared) principal goals adhere to the requisites and specifications of the Children's RAP, and subsequently analysed the content of these needs, problems and goals using the International Classification of Functioning, Disability, and Health (ICF) for children and youth as a classification system.

Table I. *The basic requisites (A1, B1, C1) and specifications (A2, B2–4, C2) of the needs, problems and goals as described in the manual of the Rehabilitation Activities Profile for children (Children's RAP)*

Qualitative requirements
A. Needs of child or proxies
A1. The concept describes a problem that hinders the child or parents in daily life or describes the wishes or expectations the child, parents or environment have regarding treatment or education.
A2. In the case of multiple needs, priorities need to be established.
B. Principal problem
B1. The concept describes a problem that hinders the child or parents in daily life or describes an aspect that hinders or stagnates the child's development.
B2. The problem is formulated on the activity and participation* level
B3. The problem refers to a changeable, trainable, compliant, or manipulable concept (concept is amendable for treatment).
B4 The problem is described in understandable language (no jargon). For each child the team needs to formulate only one principal problem per category (i.e. child, parents or environment).
C. Shared principal goal
C1. The concept describes the result or effect the team and parents aim at.
C2. The principal goal is phrased in terms of children's and parental activities. For each child only one principal goal is formulated.

*International Classification of Functioning, Disability, and Health (ICF). Geneva: World Health Organization; 2001.

To assess the content of needs, problems and goals as reported in the Children's RAP, the ICF for Children and Youth (ICF-CY) (24) was used. The children and youth version of the ICF is based on the original version of the ICF (25), which provides from a "biopsychosocial" approach to health, functioning and disability, "a coherent view of different perspectives of health from a biological, individual and social perspective" (25, p. 28). The framework provides a common language, which will facilitate the communication and information sharing across settings and disciplines (26). The use of this well-defined, extensive and universally applicable framework is encouraged in interdisciplinary disability research and provides the opportunity for making the results of research comparable (27).

METHODS

Subjects, material and setting

Parents were asked to give their consent for the use of their child's rehabilitation report if their child was diagnosed with cerebral palsy, was aged between 4 and 8 years, and attended a school for special education that was affiliated with a rehabilitation centre. We restricted our

[1]"Proxies" refers to the child's parents, siblings, peers and all significant others in the child's environment.

study to children with cerebral palsy because this is the largest group seen in paediatric rehabilitation in the Netherlands. We evaluated the Children's RAPs of 41 children (28 boys, 13 girls; mean age 6.8 years (standard deviation (SD) 1.3) as completed by 5 rehabilitation centres and affiliated local schools for special education from regions across the country. The intensity of disability varied between the participating children. The Gross Motor Functioning Classification Scale (GMFCS) (28) from these children ranged from level I (a child is able to walk and run, but has some difficulty with more advanced skills) to level V (a child has very limited voluntary movement ability). Twenty-two children were classified in level I and II, 15 children in level III and IV and 4 children in level V. The centres represented approximately 25% of our national registered paediatric rehabilitation centres. The 5 participating settings all use the Children's RAP to organize and structure the team communications and had been using the Children's RAP for more than 2 years.

The professionals (86% women; mean age 39 years (SD 10)) contributing to the treatment of one or more of the children represented 11 disciplines; 81 were associated with the rehabilitation centres and 89 with the affiliated schools. For 45%, work experience exceeded 8 years, for 22% it ranged between 3 and 8 years and for 34% it comprised fewer than 3 years.

Procedure

Because of its descriptive nature, the medical ethics committee of the University Medical Center Groningen concluded after an initial review that the study did not require a full review for ethical approval. At the start of the project, each rehabilitation centre and affiliated school was asked to assign a liaison. Following the parents' consent, the liaison provided information about the team members involved in a child's treatment and the date of the first scheduled team conference. The liaison was also responsible for forwarding a copy of the treatment plan(s) drawn up during the child's subsequent team conference.

Data collection and analysis comprised the following 4 steps:

Step 1. The first author screened the original text of each child's Children's RAP and extracted the details (verbatim notes) entered under the theme headings *child or parental needs, principal problems* and *principal goals.*

Step 2. The raw data were then organized into elements describing a single issue: per Children's RAP theme, each new issue was given a new line resulting in a final document listing all single entries per child and per theme, which will henceforth be referred to as *"(Children's RAP) concepts"*.

Step 3. To determine the appropriateness of the various formulations, we used the requisites and specifications as described in the Children's RAP manual (see Table I). For each requisite/qualification, it was determined whether the requisite or qualification was met or not (scored with a Yes or No). To ensure reliable and comprehensive evaluations, all concepts were evaluated independently by 2 raters (BJGN and HAR), who established the evaluation procedure during a pilot session based on 5 random Children's RAPs. The 2 raters decided not to consider the qualification B1 (*Concept describes a problem or stagnating (hindering) aspect*) because it could not be scored without background information on the child or its family nor the qualification B4 (*Concept is described in an understandable language (no jargon)*) because the dividing line between jargon and no jargon proved too vague as parents tended to adopt "professional language" (e.g. medical terms). After having evaluated all concepts, the 2 raters discussed differences in ratings until consensus was reached. The results reported are based on the ratings that were achieved by consensus.

Step 4. Finally, for the content analysis, the 2 raters independently linked all Children's RAP concepts to the components, domains and categories (3-digit codes) of the ICF-CY (24) (see relevant section and Table II for a more detailed description). Linking was executed in accordance with the ICF manual (25) and the Cieza et al. (29) rules for linking health-status measures to the ICF. Consensus was established and ICF-CY encoding was practised during a pilot session using 3 randomly selected Children's RAPs. Although the ICF-CY has a non-definable category to classify concepts that do not allow classification in a specific ICF-CY category, it was decided to extend the linking parameters with 3 non-definable categories. These extended non-definable categories allowed a more specific classification of concepts describing an overall aspect of the child's motor function, development or balance control that could not be assigned to any of the existing ICF-CY categories. Having analysed all Children's RAPs, the raters discussed differences until consensus was reached.

Table II. *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY; World Health Organization, 2007)*

	Part 1. Health Conditions			Part 2. Contextual Factors*
Component	Body functions (b) and Structures (s)		Activities and participation (d)	(external) Environmental factors (e)
Domains	*Body functions*	*Structures*	*Activities and participation*	
Categories	Mental Functions (b1) Sensory functions and pain (b2) Voice and Speech Functions (b3) Functions of the cardiovascular, haematological, immunological and respiratory systems (b4) Functions of the digestive, metabolic and endocrine systems (b5) Genitourinary and reproductive functions (b6) Neuromusculo-skeletal and movement related functions (b7) Functions of the skin and related systems (b8)	Structures of the nervous system (s1) The eye, ear and related structures (s2) Structures involved in voice and speech (s3) Structures of the Cardiovascular, Immunological and Respiratory system (s4) Structures related to digestive, metabolic and endocrine systems (s5) Structures related to the genitourinary and reproductive systems (s6) Structures related to movement (s7) Skin and related structures (s8)	Learning and applying knowledge (d1) General tasks and demands (d2) Communication (d3) Mobility (d4) Self-care (d5) Domestic life (d6) Interpersonal interactions and relationships (d7) Major life areas (d8) Community, social and civic life (d9)	Products and technology (e1) Natural environment and human-made changes to environment (e2) Support and relationships (e3) Attitudes (e4) Services, systems and policies (e5)

*Personal factors were not coded.

As the ICF criteria demand as precise a linking as possible, a particular Children's RAP concept may fit more than one ICF-CY code. Although classified as a single concept, the goal "Tim is able to cycle in busy traffic", for example, should be linked to both code d475 (cycling) and to code e2 (busy-traffic). Each Children's RAP concept can be linked to one or more ICF-CY codes, which results in a possible difference between number of Children's RAP concepts and ICF-CY codes. To emphasize the difference between the Children's RAP concepts and the ICF-CY codes, in the remainder of this paper we will refer to the latter as "(ICF-CY) constructs".

The inter-rater reliability of the raters' scores in steps 3 and 4 was calculated prior to the final consensus discussion by means of Cohen's kappa (see Analysis section).

The 4-step analysis described thus yielded an evaluation form listing the quality-weighted, concept-specific and ICF-CY-linked needs, principal problems and goals as derived from the 41 Children's RAPs.

International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)

We used the ICF-CY (24) to classify the Children's RAP concepts because the original ICF did not adequately capture the functional characteristics specific to the developing child (26).

As depicted in Table II, subdivided into various domains, the ICF-CY has 2 parts (Health condition and Contextual factors), each consisting of 2 separate components: (1) Body functions (b) and Structure (s), and Activities and participation (d); and (2) Environmental (e) and Personal factors. The ICF-CY provides a list of numerous codes representing detailed categories to describe, respectively, the individual's integrity of body functions and structures, the ability to perform daily-life activities and the scope of the individual's participation, and environmental factors that might facilitate or impede functioning and personal factors.

Like the ICF, the ICF-CY is a structured instrument. Its codes consist of a letter (b, s, d or e) followed by one or more numbers, where the letter refers to the domain and the subsequent numbers refer to the level of specification (chapter, paragraph, subparagraph, etc.) of the domain.

Statistics

The data were analysed using the Statistical Package for the Social Sciences (SPSS-14). We used descriptive frequency analyses on the consented data of step 3 and 4 to evaluate the quality and content of the 3 Children's RAP themes; i.e. needs, principal problems and principal goals. In all analyses, we used the data as categorized in Children's RAP concepts (single issues per child and theme) and ICF-CY constructs (ICF-CY codes), with the exception of the 2 specifications of *one principal problem and one principal goal* per child (see Table I), for which we used the raw data files and counted the problems and goals as formulated in the Children's RAP of a single child.

The Cohen's Kappa's for inter-rater reliability for steps 3 and 4 (encoding of quality criteria and ICF-CY linking) were categorized as "poor" when lower than 0.4, as "fair to good" when between 0.41 and 0.8, and "almost perfect" when exceeding 0.8 (30).

RESULTS

As explained, the 4-step analysis generated different volumes of Children's RAP concepts (used in the quality analysis) and ICF-CY constructs (used in the content analysis). Table III lists the numbers per Children's RAP theme.

Table IV presents the inter-rater reliability scores for analysis steps 3 and 4. The scores for the Children's RAP quality assessment were all above 0.4, with some scores in the "almost perfect" category (A1, A2, B and B3). The inter-rater agreement in linking Children's RAP concepts to the ICF-CY codes was "fair to good" for all 3 Children's RAP themes, both at the domain (b, s, d or e) and the category level (e.g. b1, b7, d2, e4). These results show that the assessments of quality and content of the needs, problems and goals as performed in this study can be considered as fairly reliable.

Table III. *Number of extracted Rehabilitation Activities Profile for children (Children's RAP) concepts and corresponding ICF-CY constructs for the 3 Children's RAP themes*

Theme	Children's RAP concepts (Step 2)	ICF-CY constructs (Step 4)
Needs of child and proxies	163	182
Principal problem(s)	121	147
Principal goal(s)	71	95

ICY-CY: International Classification of Functioning, Disability and Health for Children and Youth

Needs of child and proxies

For 5 of the 41 children, no needs were formulated. In the other 36 Children's RAPs, 163 need concepts were identified, of which 149 (91%) pertained to the child, 7 (4%) to the parents, and 3 (2%) to the environmental system; in 4 (3%) it was not possible to identify the person(s) concerned.

Table IV. *Inter-rater reliability scores (Cohen's Kappa) for the Rehabilitation Activities Profile for children (Children's RAP) quality evaluation and ICF-CY classification per Children's RAP theme*

Evaluation characteristic	Inter-rater reliability	
Needs of child or proxies, total n = 163		
A. Concept concerns child, parents or child's environment	0.50	
A1. Concept describes a problem or desire	0.91	
A2. Concepts are prioritized	1.00	
ICF-CY encoding (n = 182)*	*Domains*	*Categories*
	0.78	0.78
Principal problems, total n = 121		
B. Concept concerns child, parents or child's environment	0.89	
B1. Concept describes a problem or stagnating (hindering) aspect	Not possible to score	
B2. Concept is described on the activity or participation level	0.72	
B3. Concept is amendable for treatment	0.81	
B4. Concept is described in an understandable language (no jargon)	Not possible to score	
ICF-CY encoding (n = 147)*	*Domains*	*Categories*
	0.61	0.63
Shared principal goal, total n = 71		
C. Concept concerns child, parents or child's environment	0.74	
C1. Concept describes the intended result or effect	0.53	
C2. Concept is phrased in terms of parents or child's activities	0.49	
ICF-CY encoding (n = 95)*	*Domains*	*Categories*
	0.69	0.52

ICY-CY: International Classification of Functioning, Disability and Health for Children and Youth.
*n exceeds "total n" because particular Children RAP concepts linked up with more than one ICF-CY code.

According to the quality assessment of the needs, 79% of the needs met the criteria of describing *a problem* that hindered the child or parents in daily life or encompassed *wishes or expectations* the child, parents or other people in the child's environmental system had regarding the treatment (Table V, A1). In all other cases, the concepts involved *calls for information* (e.g. parents wanting information about test results or the effectiveness of special treatments for their child). Where more than one need (per child) was formulated, none of the needs were prioritized, so criterion A2 was never fulfilled.

Principal problems

For all children, one or more principal problems were formulated, resulting in 121 concepts. Almost all (97%) concerned the child, and the remaining 3% concerned the child's environmental system. In 66% the raw data files contained more than one principal problem per child that did not comply with the Children's RAP direction for including only one principal problem per child as a way to prioritize and reach conformity between team members. According to the quality criteria, Table V shows that only 24% of the principal-problem concepts were formulated in the activity-participation domain (B2) and that in 82% the formulated problem was amendable for treatment (B3).

Shared principal goals

We identified 71 concepts concerning shared principal goals. For 10 children (24%), no shared principal goal was formulated, and in 39%, the Children's RAPs mentioned 2 or more goals rather than the prescribed single goal per child. In 76% of the reports, the goal concepts concerned the child, in 9% the environmental system and in 15% the person(s) concerned remained unclear. In these latter cases, goals were formulated as general statements such as "give advice" or "attune services". Of the 71 goals, 56% met the Children's RAP criteria of goal formulation in terms of intended result/effect (C1) and 63% of the goals were formulated in terms of child and parental activities (C2). If goals did not describe an intended result/effect, they referred mainly to proposed activities of the professional team members, e.g. "make a diagnosis" or "make an inventory of possible communication devices".

Content of the three Children's RAP themes

Table VI presents the proportions in which the Children's RAP concepts (coded as ICF-CY constructs) pertained to the various ICF-CY domains.

As seen in Table VI, most of the need constructs (65%) were related to the activities-and-participation domain, whereas the problem and goal constructs were more widely distributed across the 3 domains. Of these needs in the activities-and-participation (d) domain, 23% pertained to d4, the "mobility" category. Eighteen percent of the constructs coincided with the body-functions domain and 7% with environmental factors. The remaining 9% ($n = 17$) could not be linked (ICF-CY category "non-definable").

The principal-problem constructs mostly (44%) pertained to the b domain (body function), of which 29% pertained to the category mental functions (b1); 34% matched the activities-and-participation and 6% the environmental factors domains and 16% were non-definable. In the activities-and-participation domain, the problems mostly concerned activities in the categories "general tasks and demands" (d2, 11%) and "mobility" (d4, 7%). As to the non-definable ICF-CY constructs, 6% were classified as problems, 3% as motor-system, 2% as balance and 5% as developmental problems. The latter 3 categories entailed recurring concepts that could not be linked to a specific ICF-CY code.

The constructs regarding the principal goals mostly concerned the activities-and-participation domain (38%), with 12% relating to the d2 category (general tasks and demands) and 10% to d1 (learning and applying knowledge). A good proportion (27%) referred to the body-function domain, with 18% falling within the b1 category (mental functions). Sixteen percent of the goals were linked to *environmental factors* and 19% could not be linked and were thus assigned to the 4 non-definable categories.

Table V. *Proportions (%) in which the extracted concepts for the 3 Rehabilitation Activities Profile for children (Children's RAP) themes met the quality criteria as specified in Table I*

	Quality requirements		
Children's RAP themes	A1/ B1/ C1	A2/B2/C2	B3
Needs	79	0	–
Principal problem	–	24	82
Shared principal goal	56	63	–

DISCUSSION

Treatment plans form the basis from which paediatric professionals and parents work closely together to optimize children's healthcare and treatment outcome (1, 19, 20). In the present study we identified and evaluated the quality and content of the needs, principal problems and shared principal goals as formulated in the Children's RAP of 41 children with cerebral palsy, aged 4–8 years. Although specifications and directions on the use of the Children's RAP have been formulated in the manual, the results of this study showed that adherence of formulations of needs, problems and goals to these specifications and directions was not fully achieved in all cases. For example, in none of the Children's RAPs were the children's needs prioritized and only 24% of the principal problems were specified in terms of the ICF activities-and-participation domain. As a consequence of this lack of prioritizing, it remained unclear whether parents and team members had reached conformity on the most important needs, problems and goals for the child at this moment.

One possible explanation for the non-optimal adherence of formulations to the Children's RAP specifications as found in this paper is that some of the specifications of the Children's RAP may not fit actual practices. For example, the often complex, multi-facetted problems of the children can make identification of a single major problem or goal, which determines the focus of treatment and formulation of discipline

Table VI. *The number of ICF-CY constructs per domain and category reflecting the concepts as derived from the Rehabilitation Activities Profile for children (Children's RAPs) (n = 41) with, in parentheses, the percentages of ICF-CY constructs in relation to the total constructs in that Children's RAP theme**

ICF-CY domain and category / Children's RAP themes	Needs (%)	Principal problems (%)	Principal goals (%)
Body functions			
- Body functions not specified (b)	1 (1)	1 (1)	–
- Mental functions (b1)	17 (9)	43 (29)	17 (18)
- Sensory functions and pain (b2)	2 (1)	2 (1)	1 (1)
- Voice and Speech functions (b3)	4 (2)	3 (2)	2 (2)
- Functions of the cardiovascular, haematological, immunological and respiratory systems (b4)	1 (1)	2 (1)	2 (2)
- Functions of the digestive, metabolic and endocrine systems (b5)	1 (1)	1 (1)	–
- Genitourinary and reproductive functions (b6)	–	–	–
- Neuromusculo-skeletal and movement related functions (b7)	7 (4)	12 (8)	4 (4)
- Functions of the skin and related systems (b8)	–	–	–
Total	33 (18)	64 (44)	26 (27)
Activities and participation			
- Activities and participation not specified (d)	1 (1)	1 (1)	2 (2)
- Learning and applying knowledge (d1)	17 (9)	7 (5)	9 (10)
- General tasks and demands (d2)	18 (10)	16 (11)	11 (12)
- Communication (d3)	15 (8)	7 (5)	–
- Mobility (d4)	42 (23)	10 (7)	5 (5)
- Self-care (d5)	11 (6)	–	2 (2)
- Domestic life (d6)	3 (2)	2 (1)	–
- Interpersonal interactions and relationships (d7)	5 (3)	4 (3)	1 (1)
- Major life areas (d8)	3 (2)	2 (1)	5 (5)
- Community, social and civic life (d9)	4 (2)	1 (1)	1 (1)
Total	119 (65)	50 (34)	36 (38)
Environmental factors			
- Environmental factors not specified (e)	1 (1)	3 (2)	–
- Products and technology (e1)	10 (6)	6 (4)	2 (2)
- Natural environment and human-made changes to environment (e2)	–	–	1 (1)
- Support and relationships (e3)	2 (1)	–	11 (12)
- Attitudes (e4)	–	–	–
- Services, systems and policies (e5)	–	–	1 (1)
Total	13 (7)	9 (6)	15 (16)
Non-definable			
- Non-definable	14 (8)	9 (6)	13 (14)
- Non-definable motor system	1 (1)	5 (3)	2 (2)
- Non-definable balance	2 (1)	3 (2)	1 (1)
- Non-definable development	–	7 (5)	2 (1)
Total	17 (9)	24 (16)	18 (19)

ICY-CY: International Classification of Functioning, Disability and Health for Children and Youth.
*Because percentages are rounded off, they do not necessarily add up to 100%.

specific treatment goals, extremely difficult. Are a child's mental problems, for example, more important than their motor problems? Alternatively, the professionals may have avoided defining vague or common problems or goals: they may, for instance, have opted to subdivide "to optimize motor functioning" into "to walk independently for 100 metres" and "to write legibly". However, this is only one example of a possible explanation for professionals not applying the specifications and directions on use of the instrument. In the current study we assessed adherence to specifications and did not study the reasons why specifications are not followed. Further research that focuses on the reasons for not adhering to the requisites of the instrument is needed. This research may provide insight into possible causes of current non-optimal use. The instrument might not fit with the realities of practice, but several other factors might have influenced the way (parts of) the instrument are applied in clinical practice. Team conference structures, prioritization of tasks, the availability of financial support and time to write reports and attend team conferences have earlier been related to the realization of the Children's RAP principles (31). Without knowing the reasons for non-adherence we are restricted in advising on the optimal use of an instrument in clinical practice or passing a judgement on the adaptations or training that will eventually be needed.

Nevertheless, the current results demonstrated that evaluating the actual use of an instrument and adherence to requisites and specifications of that instrument is recommended before examining the effectiveness of the instrument. Despite the specific attention that has been given to an effective, optimal implementation of the Children's RAP in Dutch paediatric rehabilitation centres (31), the current study showed that adherence to specifications was not met in all cases and that adher-

ence differed per specification and child. Therefore, to be able to objectively quantify and augment instrument effectiveness, actual use of the instrument needs to be assessed and evaluated. Efficacy evaluation studies on the use of the Children's RAP as an instrument and outcome measure is only feasible if we have insight into how the instrument is administered and if the instrument is administered consistently within and across settings. This is underpinned by earlier studies on the effect of the Children's RAP on team functioning (23) and the effect of the RAP on rehabilitation outcome in adult rehabilitation (33). Inconsistent use and inadequate implementation of, respectively, the Children's RAP and RAP in rehabilitation teams restricted conclusions on the effectiveness of the instruments. In the first study, changes in team functioning guided by the Children's RAP were identified, but varied between the participating teams, and in some teams changes were not observed. In the second study, incomplete use was mentioned as a possible cause of the failure to show improvements on rehabilitation outcome after implementation of the RAP. We thus avoid passing judgement on an instrument that several teams claim to have adopted but at present do not administer adequately and consistently.

It should be noted that our study focused only on a specific part of the Children's RAP framework, i.e. the Children's RAP report. We did not evaluate the oral communications during team conferences or informal meetings. It is possible that the written information in the reports did not adequately reflect the actual situation and practices. Perhaps a lack of time prevented teams from reporting properly or updating their records, which is why our conclusions should not be generalized to the quality of the implementation of the Children's RAP framework as a whole.

As stated earlier, the formulation of advice on improvements is currently difficult because of the lack of insight into the reasons why certain specifications are followed and others are not. However, our assessment of the Children's RAP provided some critical points on which future practices could focus. For instance, it was found that only 24% of the principal problems were formulated in terms of ICF-CY activities and participation. This finding implies that team members should be instructed to focus more on this prerequisite. Apart from the need to improve problem formulation according to Children's RAP requisites, problem prioritizing and goal-setting should also be enhanced.

As to the content of the rehabilitation reports, our analysis yielded valuable information on the actual needs and key problems of young children with cerebral palsy and on the teams' goals. The ICF-CY (24) proved very helpful in categorizing the Children's RAP concepts (Table VI). The inter-rater reliability scores for linking the ICF-CY codes to the identified concepts were all "fair to good". Consensus discussions mostly concerned the interpretation of the essence of the entries (concepts) and the best-matching ICF-CY category. Strict application of the linking rules (25, 29) and a sound knowledge of the conceptual and taxonomical principles of the ICF-CY as well as its components, domains and categories were indispensable for validly linking the concepts to the ICF-CY categories. As the interpretation of the underlying categories depends on the higher-level decisions, it was essential that encoding was performed in accordance with the ICF-CY hierarchy, i.e. from the component level via the domain level down to the best-fitting category.

The ICF-CY (24) was designed specifically for children and youths and hence allows for more developmental aspects to be encoded and pays more attention to learning and child-specific environmental aspects (26). Nevertheless, we still encountered encoding difficulties. For example, we were unsure how to assign the goal "balance control". The best-matching code seemed to be b235 (sensory functions and pain; vestibular functions), but for children with cerebral palsy, the vestibular system is not necessarily the cause of balance problems; in fact a motor cause is more likely. As mentioned in the methods section, we solved this and other linking problems by creating 3 additional non-definable categories (motor system, development and balance) for recurring aberrant themes. Despite our minor matching problems and corroborating its earlier effectiveness in classifying the diagnoses of children with disabilities (34), we found the ICF-CY useful in categorizing the needs, problems and treatment goals of children with cerebral palsy, provided strict linking rules and arrangements were adhered to. It enabled us to describe successfully the content of (intended) services.

Earlier studies provided information on the service needs of parents with disabled children (35–37). To our knowledge, ours is the first study to investigate interdisciplinary paediatric rehabilitation programmes as to the way needs, principal problems and goals are formulated. The ICF-CY classification system allowed us to define the actual contents of the Children's RAP themes for children with cerebral palsy. The identified ICF-CY constructs covered almost all ICF-CY domains and categories. The needs and problems most frequently pertained to the following categories: mental functions (b1), learning and applying knowledge (d1), general tasks and demands (d2), and mobility (d4). The principal goals were mostly linked to the categories: sensory functions and pain (b2), and support and relationships (e3). However, a closer inspection of the data indicated that the need and problem constructs were not in accordance with each other or with the treatment goal. Future child-specific analyses might help to determine whether a child's needs and principal problem are indeed integrated into the shared principal and discipline-specific goals.

In conclusion, apart from providing deeper insights into the content of rehabilitation programmes for young children with cerebral palsy treated in Dutch paediatric rehabilitation, this study demonstrates that the adherence of formulations of needs, problems and goals to the specifications of the Children's RAP is not optimal. Further research into the reasons for non-adherence is required.

ACKNOWLEDGEMENTS

This study was conducted as part of the Paediatric Rehabilitation Research in the Netherlands (PERRIN) research programme. The authors

are indebted to all the families, the 5 rehabilitation centres, Center for Rehabilitation "Beatrixoord", Het Roessingh, Revalidatie Friesland, Blixembosch and Sophia Revalidatie, and the schools for special education, Mytylschool Prins Johan Friso, Educational centre Het Roessingh, School Lyndensteyn, Mytylschool Eindhoven and Mytylschool de Pyramide, for their participation.

We thank Grieke Olijve for her help with data collection and her commitment to the ProCP study.

We gratefully acknowledge the Netherlands Organisation for Health Research and Development (grant number 1435.0011) and the National Rehabilitation Fund for their funding of and co-operation in the research project.

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